For youth with disabilities, there are many things to consider...

By Annette M. Hines

“Transition refers to a change in status from behaving primarily as a student to assuming emergent adult roles in the community. These roles include employment, participating in post-secondary education, maintaining a home, becoming appropriately involved in the community and experiencing satisfactory personal and social relationships. The process of enhancing transition involves the participation and coordination of school programs, adult agency services and natural supports within the community.”

This quote from the Massachusetts Governor’s Commission on Intellectual Disability goes to the heart of the matter of transitioning a youth with disabilities. It is a community effort. Here in Massachusetts, as in many other states around the country, we have recently concluded that it is in everyone’s best interest to help youth with disabilities achieve their maximum potential in adulthood. We have recently added a new Transition Coordinator position in the Governor’s cabinet. We have a great transition law that addresses transition from school to work. We have tackled transition needs through a separate line item in our budget. Many of our state agencies and nonprofit organizations have made achieving successful transitions a priority goal for the next three to five years.

An individual’s transition plan must look at many elements of adult living: employment opportunities, vocational and post-secondary education, where to live and with whom, independent living skills, recreation, leisure activities, social relationships, self-advocacy, health and safety, financial benefits and income planning. These elements can be addressed within the following four categories:
All students with disabilities must operate under an Individualized Education Program (IEP, which must include a Transition Planning Form by the time the student turns 16, in accordance with the Individuals with Disabilities Education Act (IDEA). Under Massachusetts law, this form must be completed by age 14. IDEA states that appropriate educational and transitional services are guaranteed, a school-based team that includes the parents and the student develops the IEP, and it is a “results-oriented” process. To get the best outcome, the team must review the student’s strengths and preferences, and it must have an action plan that discusses instruction, related services, community experiences, employment, daily living skills and functional vocational evaluations. Many times, we see a Transition Planning Form that merely repeats the same goals listed in the IEP. This does not satisfy the law. Transition goals are separate from IEP goals because they look at more than just the educational process. This is when a parent’s and student’s vision statement, which is a required part of the IEP, becomes very important. A student may state that he wants to be a professional baseball player. Well, not all people have a skillset to be a professional athlete. But there are ways to include the love of baseball into this student’s life and employment plans. Perhaps the student can volunteer for the local team, or maybe he can work at a sports store or a stadium. Once you have the vision, mapping out the process through individualized assessments and an action plan becomes a little easier.

Next, we would determine the appropriate transition agency that would deliver adult services to the student. In Massachusetts, the two most likely agencies are the Department of Developmental Services, which serves people with intellectual disabilities, and the Massachusetts Rehabilitation Commission, which serves just about everybody else. These agencies have programs that may be appropriate for an individual, and these programs have income, asset and other eligibility rules that are important. In general, they serve individuals with disabilities who are of low
income and resources. The other two benefits that will likely become extremely important for adults with disabilities will be Social Security Income payments and your state Medicaid program. These two programs will typically establish a baseline of eligibility for other various educational, housing and support programs in your state. Therefore, eligibility for these programs is a gateway to many other benefits.

Often when I meet with a family, they may initially feel that they do not need to worry about qualifying for public benefits because they believe they have planned adequately and saved money for their disabled child, or the disabled child has wonderful siblings who will take care of him or her. Unfortunately, public benefits are still very important for many people with disabilities. Some reasons:

- Predicting the cost of your disabled child’s future needs is so difficult that saving enough for his or her lifetime is almost impossible.
- You cannot depend on your other children to support the person with the disability. There are too many things that can go wrong in siblings’ lives that could prevent them from doing so, including their own disability, divorce, credit issues and their own or their family’s health issues.
- Some programs depend on public benefits eligibility to enroll, and you may not be able to pay for them privately.
- You want to be declared eligible for benefits under today’s eligibility rules because every year that goes by, the rules make it harder and harder to qualify. Medicaid is a very helpful program for many people with disabilities. It offers care and medical supports that most private insurers do not pay for, such as personal care attendants, nursing, incontinence supplies, medications, equipment and services. In Massachusetts, we have signed on to three federal waiver programs for adults, which combined with our state agency, the Department of Developmental Services, provide a valuable bundle of services and financial support for our most vulnerable population to continue living in the community. However, this waiver program requires you to be of little means in terms of income and assets.
To stay under these income and asset limits, most planners for children with special needs will use two different kinds of special needs trusts to allow a family, or even disabled persons themselves, to put aside resources to help support them and still qualify for public benefits. These trusts, if appropriately drafted, do not count as assets of the person with the disability.

The most popular trust is typically known as a Supplemental Needs Trust (SNT). This trust is funded with other people’s money, not money of the person with the disability. In most instances, the trust is funded at the death of the parents of the disabled person, but may also be funded by the parents during their lifetimes. The trust may also hold gifts from anybody else who would like to provide support for the disabled beneficiary. This trust is set aside for the benefit of the disabled person and must be completely discretionary. In other words, the trustee has the absolute authority to decide what distributions to make from the trust. The disabled person may not be a trustee. The trust is held for the lifetime of the disabled beneficiary, and the original creators of the trust get to decide the successor trustees and beneficiaries. In addition to that trust, we also have a provision under the Social Security laws that allows disabled people to take their own money and put it in a trust that will be available for their benefit but will not count against them when qualifying for public benefits. This is typically known as a (d)(4)(A) trust or an OBRA 93 trust. It seems impossible that the government would allow this, but there is a catch. If a disabled beneficiary does use a trust of this type, when he dies, the trust must name as the successor beneficiary each state that has provided Medicaid benefits to the disabled beneficiary. The state Medicaid agency may recoup or “recover” all costs of providing medical care to that disabled beneficiary for his entire lifetime. This means that if a person with a disability passes away and there is $100,000 left in the trust, a state may place a lien on those assets
to satisfy any medical payments it has made throughout the person’s lifetime. In addition, there are other significant differences between a (d)(4)(A) and a SNT. A (d)(4)(A) trust can only be established by a parent, grandparent or legal guardian of the disabled beneficiary or by court order. The trust can only be established and funded for a person under the age of 65. Lastly the trust must be irrevocable, meaning it cannot be changed or terminated.

Although these requirements can be very daunting, a (d)(4)(A) trust is very helpful to a person with a disability under certain circumstances to that the person does not lose valuable benefits provided by the federal or state government. The kinds of circumstances I often see are:

- Estate planning mistakes resulting in money left directly to the individual with disabilities.
- Receipt of child or adult support payments.
- Settlements from accident or other civil tort claims.
- Lottery winnings.

The last area reviewed is whether the parents or other trusted adults need to remain involved in some legal capacity with the person with the disability. This could include either guardianship, conservatorship or durable powers of attorney and health care proxies.

When children turn 18, they become their own legal persons. Regardless how severe a disability, there is no presumption of incapacity. Only a court can determine whether a person is incapacitated, to what extent, whether a guardian should be named and who should be named. This action does not take place automatically; it must be initiated by some interested person. Each state requires medical documentation of the incapacity and sets its own standard for determining whether incapacity exists.

The most important fact for family members to remember is that without this legal finding of incapacity, there are confidentiality issues around health care and financial information of the disabled person. A parent can no longer automatically
make health care decisions or perform banking tasks for their child. It often comes as quite a shock to family members when they realize this.

To decide whether guardianship or other legal authorities are appropriate, you must review your child’s individual needs, strengths, weaknesses and risks. A specific diagnosis, or the fact that a person has an intellectual or physical disability, does not mean he is incapacitated. The determination of incapacity is very individualized.

Considering whether guardianship can be avoided is a valuable process. Guardianship can be a cumbersome and expensive undertaking. In most states the process is public, meaning it happens in open court, and the pleadings filed with the court, except for medical information, are open to the public. The legal determination of incapacity eviscerates the option of self-determination. Other alternatives to guardianship, such as health care proxies, powers of attorney and other agency appointments, are less intrusive and should be reviewed.

However, there are times when guardianship cannot or should not be avoided. As the mother of a severely disabled teenager, and in my law practice, I usually err on the side of guardianship because I find it to be a more cautious approach. The statistics of financial and physical abuse and neglect of the disabled in our communities are frightening. Many of our disabled family members may be vulnerable and at risk. Sometimes, protection is needed for the disabled individual by court intervention and oversight. Perhaps she lacks the capacity to validly execute a durable power of attorney or health care proxy. Or, in rarer cases, a court-appointed fiduciary is needed because there is no interested party available to serve as an agent under a durable power of attorney or a health care proxy. Each state has its own laws regarding health care proxies and durable powers of attorney, but in general, the documents are:
• **Durable Power of Attorney**, which governs financial decisions and gives the agent the authority to act on the part of the principal (the person with the disability). It is typically a concurrent power, meaning that the agent and the principal can act simultaneously; cannot be used to void contracts and easily revoked by the principal.

• **Health Care Proxy**, which governs health care decisions and gives the agent the authority to act on the part of the principal. Typically, it is a springing power, which goes into effect only when a physician says so. It cannot be used for day-to-day health care decisions and is easily revoked by the principal.

With each of these, the principal has a very low threshold for capacity to sign the documents. They must only understand at a very basic level the authority and to whom they are giving it. The difficult aspect of this for many people I work with is the fact that it is easily revoked. If you have a child that is variable in any way, this may not be the solution for you.

In conclusion, decisions regarding transition are very difficult to make, and the planning requires time and good support people on your team. The process should start when the person with the disability is a teenager, with the hardest work being done around age 17. The plan should be flexible and evolve over time. An attorney specializing in this field, a financial planner and a care manager can add enormous value when planning for the transition to adulthood of a youth with disabilities.

Note: This material is intended to offer general information and should not be relied upon as specific legal advice.
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In addition to her membership in the Massachusetts Bar Association, she is a board member of the National Academy of Elder Law Attorneys (NAELA), a member of the National Academy of Special Needs Planners (ASNP) and the Massachusetts Association of Women Lawyers (MAWL). Recognized as a Distinguished Citizen by ARC Massachusetts and cited for public service by both the Massachusetts State Senate and House of Representatives, Ms. Hines works tirelessly on behalf of people with disabilities. Attorney Hines served as President of the Massachusetts Association of Women Lawyers for 2008-2009 and has been awarded 2016 “Top Women of law” (MA Lawyers Weekly Newspaper). She has been designated a Massachusetts Super Lawyer since 2014.